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Quality of life in aphasia: An international perspective.
A survey of clinician views and practices from 16 countries.

Short title: Quality of life in aphasia: An international perspective.

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Abstract

Objective: To gain an insight into speech and language therapists' perspectives and practices on quality of life in aphasia.

Participants and Methods: The International Association of Logopedics and Phoniatrics Aphasia Committee developed a survey questionnaire, which was delivered on-line, anonymously, through SurveyMonkey (November 2012 – April 2013) to clinicians working with people with aphasia in 16 countries across the world.

Results: A large number of speech and language therapists responded to the survey, with 19/21 questions answered by 385 – 579 participants. Clinicians were well informed on what constitutes quality of life and viewed it as a complex construct influenced by health, participation, in/dependence, communication, personal factors, and environmental factors. In their clinical practice, they considered quality of life as important, used informal approaches to explore it and aimed to address quality of life goals; yet the majority did not evaluate quality of life in a systematic way.

Conclusion: There is a need for training on quality of life to facilitate speech and language therapists to incorporate quality of life outcome measures in their interventions. There is also a need for further research on what interventions improve quality of life in aphasia.

Introduction

Aphasia is a language disability caused by organic damage to the brain, most commonly a stroke. It can affect all language modalities, i.e. speaking and expressing oneself, understanding what other people say, reading and writing. It may also affect non-verbal communication modalities such as gestures. It is estimated that 35% of people who suffer a stroke have aphasia early post-stroke (1), while 15% remain aphasic in the long term (2).

Aphasia has a profound impact on quality of life. A recent systematic review explored factors that predicted poorer health-related quality of life in people with aphasia post-stroke. The review covered 14 studies (three qualitative and 11 quantitative reports). The qualitative studies comprised 98 and the quantitative studies 742 participants with aphasia. In the quantitative studies, emotional distress/depression, extent of communication disability and aphasic impairment, presence of other medical problems, and activity levels were the main factors affecting quality of life. Social factors also emerged as important. Themes drawn from qualitative studies supported these findings and included looking to the future/having a positive outlook, verbal communication, body functioning, and people and social support as positive factors in quality of life with aphasia. They also identified adaptation of personal identity and development of a collective identity, and working to remove the barriers that people with aphasia face as ways to reduce aphasic disability and live successfully with aphasia (3).

Emotional wellbeing and social participation and social support are aspects of quality of life particularly affected in aphasia. The prevalence of

depression in people with aphasia in the long-term post-stroke has been estimated at 62-70% (4). In terms of social wellbeing, people with aphasia perform fewer social activities than non-aphasic controls and derive less satisfaction from them (5). They also feel less engaged in their social activities and less integrated (6) and are at risk of losing contact with their friends and their wider network and becoming socially isolated (7-10).

These psychosocial factors have important clinical implications. Depression after stroke impacts significantly on long-term functioning and quality of life (11), reduces the effects of rehabilitation services, and leads to higher mortality rates (12). On the contrary, maintaining social networks is important after stroke, as friendships can be a protective factor, especially for older people. A meta-analysis of studies on factors affecting wellbeing in later life suggested that contact with friends was associated with higher subjective wellbeing (13). Additionally, friends-based social networks enhance survival in the elderly (14).

Despite this evidence on the impact of aphasia on people's lives and the importance of considering this impact in rehabilitation, studies from different countries suggest that measures of quality of life and related factors are not routinely used in clinical practice (15, 16). Moreover, systematic reviews of aphasia therapies have indicated that quality of life outcomes are not typically considered (17, 18).

To understand why this may be the case and to begin to consider how quality of life can be successfully addressed in aphasia interventions, we need to gain an insight of what speech and language therapists think about quality of life

and what they do about it in their practice. In this study we ran an international survey to explore the perspectives and practices of speech and language therapists in relation to quality of life. The survey addressed the following questions:

- a) How do speech and language therapists define quality of life and what do they see as its important aspects?
- b) Whether and how do they address quality of life in their intervention with people with aphasia?
- c) What quality of life assessments and outcome measures do they use?
- d) What they see as important research questions in this area.

Methods

The IALP aphasia committee developed a survey questionnaire to investigate speech and language therapists' perspectives and practices on quality of life in aphasia in different countries. The survey was anonymous and delivered on-line through SurveyMonkey (November 2012 – April 2013) to speech and language therapists working in the countries involved in the survey (see procedure below).

Survey questions

The survey comprised 21 questions (see appendix 1). Four of the questions were open questions (6,9,13,15), four were yes/no questions

(14,16,17,18), and in the remaining 13, respondents selected an answer from a list of options. The language of the survey was English but for the Finnish respondents the questionnaire was translated into Finnish. The first section (questions 1-8) collated demographic information on the respondents and information on their work setting and their experience working with aphasia. The second section (questions 9-11) asked how the respondents defined quality of life, what quality of life perspectives they saw as important, and which quality of life domains they considered important to incorporate into their practice with aphasia. The third section (questions 12-20) sought information about the respondent clinical practices, i.e. their rehabilitation aims, whether and how they explored quality of life with their clients with aphasia, what measures they used, and what they saw as barriers and facilitators in incorporating quality of life goals in their practice. The fourth section (question 21) asked the respondents to rank the three most important research areas for quality of life in aphasia.

Procedure and participants

Each member of the IALP Aphasia Committee and author team acted as a principal investigator in the country where they were located and was responsible for ethics approval and administration of the survey in their country. They were based in the following countries: Australia (LW), Cyprus and Greece (FC), Finland (AK), Slovenia (NZ), South Africa (CP), United Kingdom (KH, SH), United States of America (PB, AR). The target participants were speech and language therapists working with people with aphasia. In each country, an email with information about the survey including a link to the survey was distributed through contact lists, voluntary organisations and professional associations of

speech and language therapists working with aphasia. For instance, in the UK the survey was sent out to the membership lists of the British Aphasiology Society (BAS) and Adult Neurology and Aphasia Special Interest Groups; in the USA to members of the discussion group of Special Interest Group 2 of the American Speech-Language-Hearing Association; and in Greece and Cyprus, to all registered speech and language therapists. Snowballing was also used, i.e. those who received the invitation email were asked to forward it to their contacts if they wished. This resulted in speech and language therapists from 16 countries taking part in the survey.

Data analysis

Descriptive statistics were used to describe the participants in the study and their responses to the survey questions. For open-ended questions qualitative content analysis was used (19).

Results

Response rates

It is impossible to calculate accurately the response rates in this survey, as in some countries mailing lists used (e.g. registered speech and language therapists) included people not working with aphasia; and snowballing was used, so we cannot know how many people received the invitation email. Yet, for some countries a response rate can be estimated. In the UK, those with an interest in aphasia, and likely to complete a survey on aphasia, are also likely to be BAS members. BAS had 497 members at the time of the survey and 171 responded to the survey so we can estimate the UK response rate at 34.4%. In

Finland, the survey was sent altogether to 158 speech and language therapists out of whom 64 responded; the response rate would therefore be 40%.

Participant characteristics (questions 1-8)

581 speech and language therapists took part in the survey, but not all of them answered all the questions. Section one questions (1-8) were answered by 531-579 participants; section two questions (9-11) by 427-443 participants; section three questions (12-20) by 104-424 participants; and the last question (21) was answered by 385.

Participants' demographic characteristics are detailed in table 1. The respondents represented a wide age distribution, with the groups evenly distributed across the decades from 21 to 60 years of age. The group included primarily female respondents, as is typical of the professionals who treat individuals with communication disorders around the globe. The ethnicity of the sample was queried with an open-ended question, which led to responses that included the geographic ethnicity, while several, particularly those from the United States, responded with their race rather than ethnicity. The majority of the sample was continental European or British (68%). A portion (18%) called themselves white. Likewise, the country that the respondents were located in for their professional practice was primarily European (U.K., Finland, Greece, Cyprus, Slovenia), with a good number also from North America (U.S. and Canada) and the South Pacific (Australia and New Zealand). About half of the respondents reported to be monolingual and the other half were multi-lingual. Many reported to be monolingual non-English, and yet they responded to this English language survey, suggesting that more individuals were proficient in

another language than are reported in Table 1.

[table 1 about here]

Three survey questions asked the respondents about their professional experience and work setting (Table 2). Numbers of years of service ranged from 0 (implying that they were students in training) to more than 30 years of experience, with the majority (55%) reporting less than 10 years of service to the profession. The majority of participants reported they worked in inpatient or outpatient rehabilitation settings (40%), with others distributed across other clinical settings. Most respondents (87%) reported seeing at least some clients with aphasia each week, with the majority reporting 1-5 clients with aphasia per week.

[table 2 about here]

*Quality of life: speech and language therapists' definitions and perspectives
(questions 9-11)*

In the first question in this section (Q9), respondents were asked to define quality of life. A qualitative content analysis of their responses revealed two major themes: conceptualization and influencing factors.

Theme 1: Conceptualisation. The first theme related to the way in which respondents conceptualised quality of life as a construct. Respondents described quality of life as a paradigm which is both complex and individual. Complexity related to the multiplicity of factors perceived to influence quality of life and to the challenges inherent in defining the concept.

“Quality of life is a collection of factors...”

“A difficult concept to put into words...”

Respondents also conceptualised quality of life as a construct which is subjective and highly individual in nature.

“Quality of life is different for everyone and dependent on individual circumstances...”

Theme 2: Factors influencing quality of life. The following factors were identified by respondents as key influences on quality of life: health, participation, in/dependence, communication, personal factors, and environmental factors (figure 1).

[figure 1 about here]

Respondents identified physical and psychological/emotional *health* as key factors in achieving and maintaining quality of life. The importance of physical well-being was highlighted in general terms, e.g. “Good physical health”, and more specifically in terms of acceptability of pain levels, amounts of sleep and rest, energy levels, nutrition and levels of stress. Psychological/emotional health was also identified as a key determinant of quality of life. A wide range of factors were discussed including the importance of experiencing positive feelings such as happiness, fulfillment, satisfaction, and enjoyment. Respondents also acknowledged the significance of positive feelings relating to self, such as self-worth, self-respect, self-acceptance, confidence and dignity. Freedom from negative feelings was also recognised as important, for example having, “freedom from anxiety”.

Levels of *independence* or dependence in a range of life areas were identified as important determinants of quality of life. Independent mobility, participation in activities of daily living, and decision making; as well as personal independence on a broader scale (e.g. freedom from oppression) were discussed as key factors which influence a person's quality of life.

"Independent in mobility."

"...able to make decisions of one's own life."

"A high-quality life is also a life of freedom."

Participation in relationships, life roles and activities were described as key elements in quality of life. Respondents highlighted the importance of family relationships and friendships and the key role of employment and contribution to one's community and society in general.

"...having a loving family and close circle of friends."

"The ability to fully participate in and enjoy everyday activities."

"...ability to be contributing member of a community."

Communicative ability was emphasised as an important influence on quality of life. This encompassed the ability to communicate basic needs and wants, and extended to high level communication activities such as sharing thoughts and feelings. More broadly, respondents talked about the importance of access to multi-modal communication and possession of communication rights, such as freedom of speech.

Personal factors were identified as influencing quality of life. Respondents discussed the role of personal beliefs (philosophical and cultural), spirituality and religion, outlook on life, and life aspirations in achieving quality of life.

“Able to pursue my dreams and ambitions.”

Finance, access, safety and security, geographical location, ease of living and richness of environment were identified as key *environmental factors* influencing on quality of life. Respondents discussed how factors such as standard of living, societal discrimination, and having an environment compatible with one’s needs impacted on quality of life.

“Having good health and access to excellent healthcare.”

“Feeling safe and secure in your environment.”

“...removing barriers to carrying out activities.”

The next survey question (Q10) asked respondents to identify which of the following perspectives on quality of life they considered important: overall quality of life, health-related quality of life, subjective and psychological well-being and positive or negative affect (see Table 3). Overall quality of life (86%), health-related quality of life (80%) and subjective and psychological well-being (78%) were all rated highly by respondents; positive or negative affect was identified as less important (26%). Respondents were also able to provide alternative suggestions to the four listed options and noted that perspectives relating to financial security and societal contribution were important. Respondents acquiesced that all of the perspectives outlined above

were important and inter-related, again also noting the subjective nature of quality of life.

[table 3 about here]

In the last question of this section (Q11) respondents were asked to identify which quality of life domains should be incorporated in speech and language therapy practice. The top four rated domains were communication (97%), daily activities (90%), interpersonal relationships (85%), and in/dependence (85%). Other domains considered important by respondents included: social activities, adjustment and acceptance, self-image and self-worth, creative expression, altruism, intellectual growth, personal growth, future goals, sexuality, informed choice and decision making, role change and participation in a meaningful vocation.

Quality of life: speech and language therapists' clinical practice (questions 12-20)

Participants were asked how they used quality of life measures with people with aphasia (Q12). 423 participants responded to this question. A third 33% did not use quality of life measures with people with aphasia, 10% used quality of life measures as assessments, 19% used them as outcome measures and 27% used them as both assessments and outcome measures. The remaining 10% chose the response option 'other'. Of these, 55 respondents further specified their approaches. Qualitative content analysis generated two main themes, with associated sub-themes:

Quality of life for rehabilitation planning (informal assessment; patient self-rating). Where formal measures were not used, SLTs were nonetheless conscious of quality of life issues, and their approaches were informed by a variety of models and methods, including patient self-rating and subjective reports.

“I only use subjective evaluation of QoL. For instance, conversation on the subject”

“Everyone’s idea of their own QoL was different and it had to be part of the process for shaping their therapeutic programme to help set goals and aims for both the person and the therapist alike”

They addressed assessment, goal setting and therapy planning through on-going discussion with patients and families, relying on patient self-report and scales or records developed by themselves.

“I use rating scales and discussion, but do not have any formal measures of QOL. I would like some!”

“I use the CAT QoL measures...more about the process than the outcome and where they are in the process”

Quality of life for evaluation. Evaluation was discussed in terms of progress review and goal adjustment, as well as measurement of ‘outcome’

“Only ad hoc / informal measures used as part of evaluating progress of therapy then re-directing / modifying goals and input as required”

“As an outcome measure but it is difficult to find one that actually involves all possible QoL parts”

“An outcome measure would be useful. I should use one”

The emphasis on informal approaches is echoed in responses to Q13. When asked which measures or assessments they used, 98 of the 215 respondents mentioned “discussions with patients and / or families” or “informal assessments developed by the therapist”.

“[I use] questionnaires and discussions with patients and their families. There are no formal assessments available at our institution”

Of the 128 responses using specific formal measures, most mentioned more than one. The most frequently reported measures were the Stroke and Aphasia Quality of life Scale (SAQOL-39, 24, 25) (n=28), the Therapy Outcome Measures (TOMS, 26)) original and Australian version (n=25), the Visual Analogue Self-Esteem Scale (VASES, 27) (n=24), and the Communication Disability Profile (28) (n=24). Other frequently mentioned measures were the the ASHA Quality of Communicative Life scale (QCL, 30) (n=12), and the Living with Aphasia: A Framework for Outcome Measures (A-FROM, 31) or Assessment of Living with Aphasia (ALA) (32) (n=12). Surprisingly, the Communicative Effectiveness Index (CETI, 29) was mentioned by 18 respondents although it is not a measure for quality of life or related concepts.

The majority of respondents (74%, n=307/413) considered quality of life to be the main aim of aphasia rehabilitation (Q14). For those that did not (n=104), qualitative analysis of Q15: “what do you consider to be the primary

aim of aphasia rehabilitation” showed that quality of life aims were still relevant. Two main themes, with associated sub-themes were generated through analysis of these responses (n=104):

Communication (communication-focus; language focus) was the first theme. Respondents overwhelmingly focused on the achievement of functional or effective communication as the primary goal of aphasia rehabilitation. This was often linked to achieving social interaction and participation in family and society. Many respondents pointed out how this aim enabled people with aphasia to achieve meaningful quality of life goals or get back to living successfully with aphasia, but that quality of life was not a primary goal. Some therapists saw work on language impairment and regaining lost skills as a means of achieving quality of life goals.

“Assisting the pt. to achieve the most functional level of communication/meaningful social interaction possible with those most important to them and within the community in which they live”

Support (person-centered focus; supporting patients and families) was the second theme. There was a clear emphasis on person-centred care and goal setting, with therapists having an important role in enabling people with aphasia to cope and adapt to life after stroke. Therapists also addressed issues of patient autonomy and choice. Psychosocial issues such as improving self-confidence or self-esteem, and addressing “some of the chaos and fear associated with loss of language” were also considered important.

“Creating and reaching short-term and long-term goals that aim to

improve confidence, ability, and overall approval of self”

Work in supporting carers was mentioned less often, but there was a role in supporting carers and providing information and advice.

“Information provision of the PWA and their family is also very important, as well as ensuring follow-up therapy and supports are in place”

In question 16, 69% (n=281/406) reported that they explored quality of life issues in an interview format, and 63% (n=254/406) as part of an initial assessment (Q17). Sixty-eight percent of respondents (n=278/406) explicitly included quality of life goals in their therapy (Q18).

Respondents were asked to consider the main barriers (Q19) and facilitators (Q20) to including quality of life goals in their practice. The main barriers were reported as: organisational (e.g. policy and procedural barriers, staffing barriers, resources) (n=211); societal (e.g. inadequate health care funding, cultural differences, attitudinal barriers) (n=196); personal (n=106); other (n=72); none of these (n=64). The main facilitators were reported as: personal (n=271); organisational (n=123); societal (n=109); other (n=49); none of these (n=39).

Qualitative analysis of the ‘Other’ responses in relation to barriers (Q19) produced three main themes: institutional context; patient and family factors; and professional and personal factors

In terms of *institutional context*, the main reason for speech and language therapists not incorporating quality of life issues or assessments into their

practice was related to working in acute settings. They argued that the state of health or well-being of patients at that point meant that quality of life issues were not considered relevant by the patients, their families, colleagues or, generally speaking the employing institution.

“see patients in the acute/early rehab phase in a hospital setting when their priorities are usually different - often too soon for them to be considering their long term quality of life as only just coming to terms with their new identity/ living with a disability”

Speech and language therapists in this setting tended to focus on patient safety and impairment / language focused interventions. There were also issues of time constraints and caseload management in these settings. Some mentioned a lack of appropriate quality of life tools for their work context.

“time required to really genuinely goal set is not resourced adequate and a fear that you cannot tackle the bigger issues in the time you have available”

Frequently mentioned were *patient and family factors*, i.e. attitudes and expectations, which affected their engagement with quality of life issues. Managing expectations and agreeing meaningful goals was an important issue.

“Managing patient expectations and making quality of life goals realistic”

Respondents also raised *professional and personal factors*. They mentioned a lack of professional guidelines and their own competencies in quality of life matters.

“I occasionally will add the term quality of life in a long term goal, but I

don't have a means of making it measurable”

“I don't think there is an agreed useful clinical tool that covers all people with aphasia that enables routine data collection in clinical practice”

In terms of facilitators, qualitative analysis of the ‘Other’ responses from Q20 produced two main themes: patient and family factors and professional values.

Incorporating quality of life goals was facilitated by *patient and family factors*, such as a positive attitude where clients were motivated to address quality of life issues within the context of a supportive family.

“The client's expressed desire for this, or favourable response to this”

“Ability to engage in dialogue about this with pwa, family and carers”

Speech and language therapists *professional values* and skills appeared to be particularly important, especially within a supportive institutional context, where quality of life was viewed as a valid goal of rehabilitation, allowing time and resources to be directed towards quality of life efforts. In addition, community and other agencies were thought to provide resources and opportunities for quality of life aims to be addressed.

“Also time, effort and having a good relationship based on equality, respect and good listening skills”

“The service I work in aims to have a holistic, quality of life driven approach to intervention with clients, which facilitates incorporation of QoL

goals in my own practice”

Quality of life: research priorities (question 21)

Respondents were asked to identify the three most important research areas for quality of life in aphasia (table 4). The top three answers were: efficacious interventions to improve quality of life in aphasia (58%), what factors influence quality of life in aphasia (47%), and how the quality of life of people with aphasia is affected by aphasia (43%). The most important area identified, efficacious interventions to improve quality of life in aphasia, was further boosted by 30% of respondents who identified comparative studies of different interventions to improve quality of life with aphasia as important, and 23% who advocated for systematic reviews of interventions to improve quality of life in aphasia. The quality of life of carers / family was also seen as an important area for research (31%), whereas cost-effectiveness analyses (19%) and comparisons with other disorders (8%) were seen as less important.

[table 4 about here]

Eleven people (3%) chose ‘Other’ and individual comments included exploring cultural differences; education on aphasia so that those on ethics committees know that people with aphasia can give informed consent for participation in research; ensuring funders are prepared to reimburse therapy that aims to improve quality of life; training speech and language therapists on how to incorporate quality of life in treatment; and exploring the efficacy of interdisciplinary teams on quality of life rather than a single approach.

Discussion

This study explored speech and language therapists' definitions and perspectives on quality of life; their clinical practice in relation to quality of life; and their research priorities in this area. A large number of speech and language therapists responded to the survey, with 19/21 questions answered by 385 – 579 participants. The majority (74-76%) responded to the questions on defining quality of life and they saw it as a complex and highly subjective construct influenced by health, participation, in/dependence, communication, personal factors, and environmental factors. Respondents endorsed generic and health related perspectives on quality of life, as well as subjective wellbeing. They identified communication, daily activities, relationships and in/dependence as key areas to work on in their interventions. In terms of clinical practice, 70-73% of the sample answered these questions. Of those, the majority (74%) considered quality of life the main aim of rehabilitation, and explored it at initial assessment (63%) and in interviews (69%) and included quality of life goals in their intervention (68%). 37% of the sample used specific outcome measures and /or informal methods to measure / assess quality of life. On barriers and facilitators in incorporating quality of life goals in their practice, 68% responded: the most frequently mentioned barriers were organizational (e.g. policy and procedural barriers, staffing barriers, resources) (54%) and societal (e.g. inadequate health care funding, cultural differences, attitudinal barriers) (50%); whereas the most frequently mentioned facilitator was personal (e.g. professional value system, education or training in quality of life) (69%). Lastly, the respondents identified three most important areas for further research: the top answers were

interventions to improve quality of life in aphasia (58%), factors affecting quality of life (47%) and in particular the impact of aphasia per se on quality of life (43%). These findings will be discussed in turn.

Speech and language therapists' saw quality of life as a complex and subjective construct influenced by health, participation, in/dependence, communication, personal factors, and environmental factors. Activity restrictions featured prominently under 'independence', and relationships, family and friendships and participation in life roles featured as important under 'participation'. This conceptualization is in line with widely accepted definitions in the literature, suggesting that speech and language therapists are well informed on what constitutes quality of life. For example, the World Health Organization's definition of quality of life (20) includes: *"It is a broad ranging concept affected in complex ways by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment"* (p. 1405).

The respondents on this survey also seemed well informed on factors affecting quality of life in people with aphasia. They identified communication, activities, relationships and in/dependence as important factors to work on with people with aphasia. These areas resonate with the priorities of people with aphasia for intervention, which include communicating opinions, independence and respect, and participation in a range of activities (33). Moreover, addressing these areas in intervention could have an impact on quality of life as communication impairment, activities, emotional distress, and social aspects

were important and affected quality of life in people with aphasia in a recent systematic review of research reports in this area (3).

A third of the respondents did not answer the questions on their clinical practice in relation to quality of life. Those that did, saw quality of life as a main goal of rehabilitation, which accords with professional bodies' guidelines (34, 35); and they explored quality of life and included quality of life goals in their interventions. Some identified communication as the main goal of rehabilitation and suggested that improved communication may be a mediating step to improving quality of life. They saw quality of life aspects, such as improving social interactions and addressing psychosocial issues e.g. confidence and self-esteem as essential goals of intervention.

Two hundred and seventy five respondents reported using quality of life measures in their practice, yet when asked about what specific measures they used, 128 (22% of the overall sample) were able to name specific measures. The picture that seems to emerge from this data is that speech and language therapists see quality of life as important and use informal approaches in relation to quality of life in their practice, yet they do not evaluate quality of life in a systematic way. This has important clinical implications. If therapists do not use quality of life outcome measures, then they do not measure whether their clients attain their quality of life goals; and the effectiveness of their interventions on quality of life cannot be evaluated.

Participants identified mostly organizational (e.g. policy issues) and societal (e.g. adequate health care funding) barriers in incorporating quality of life goals in their clinical practice. Responses to the 'other' category supplemented this picture by including comments on 'lack of professional

guidelines and own competencies’ and lack of tools or ‘means to make it (quality of life) measurable’. Yet, professional guidelines do advocate working on quality of life goals (34, 35) and policy is shifting with international directives requiring evidence on the effectiveness of interventions on patient reported outcome measures (PROMs) on quality of life and health status. For example, the National Institute for Health PROMIS initiative in the United States <http://www.nihpromis.org/> and the National Health Service PROMs in the UK <http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/aboutproms.aspx> where PROMs are routinely collected in order to compare services and improve the quality of care. This shift means that quality of life outcomes are gradually becoming not desirable but essential outcomes to collate.

Speech and language therapists responding to this survey also seemed to have limited knowledge of existing resources and tools to measure quality of life, such as the SAQOL-39, the VASES, the TOMS, the CDP, the ALA, which were mentioned by only a few of the participants. This resonates with the literature in the area on limited use of such measures in clinical practice and research (15-18). There seems to be a pressing need for education and training on quality of life, which was also identified by the respondents in this study as a main facilitator in incorporating quality of life in clinical practice. Education and training can raise speech and language therapists’ awareness of current drives for addressing quality of life in intervention; of factors affecting quality of life (3, 36); and familiarize them with resources and outcome measures and how to incorporate these into their clinical practice.

The respondents in this survey identified the effectiveness of speech and language therapy interventions on quality of life as a top priority for further

research. Indeed, there is limited evidence on what speech and language therapy programmes lead to gains in quality of life. Encouragingly, currently ongoing trials include either generic (EuroQoL) (37) quality of life measures (38), or stroke and aphasia specific measures (SAQOL-39g) (39, 40), so this evidence will soon begin to emerge. Additionally, other interventions have specifically targeted psychosocial wellbeing in people with aphasia (41, 42). It is argued that speech and language therapists, given their professional expertise and communication skills, may have a special role to play in working with people with aphasia on their emotional and social wellbeing (see Northcott et al., this issue).

Conclusion

This international survey explored speech and language therapists' perspectives and clinical practices in relation to quality of life in aphasia. Speech and language therapists were well informed on what constitutes quality of life and viewed it as a complex construct influenced by health, participation, in/dependence, communication, personal factors, and environmental factors. In their clinical practice, they considered quality of life as important, used informal approaches to explore quality of life and aimed to address quality of life goals; yet the majority did not evaluate quality of life in a systematic way. There is a need for training on quality of life to facilitate speech and language therapists to incorporate quality of life outcome measures in their interventions. There is also a need for further research on what interventions improve quality of life in aphasia. Building up this evidence base both through clinical practice and research will allow speech and language therapists to target their interventions

more effectively in order to help people with aphasia meet their life goals and live successfully with aphasia.

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Table 1: Demographic characteristics of respondents (N=581)

Age (n=579)	Gender (n=579)	Ethnicity (n=579)	Languages (n=579)	Country Location (n=531)
<30: 21%	Female: 93%	Europe: 42%	Monolingual: 55%	UK: 32%
30-39: 32%	Male: 7%	UK: 26%	Bilingual: 21%	East. Europe: 23%
40-49: 26%		North American: 2%	3 or more: 23%	North. Europe: 14%
≥50: 21%		Asian: 2%	Unknown: 1%	South Pacific: 13%
		Pacific Island: 5%		North Amer: 12%
		Black: 0.2%		Africa: 6%
		White: 18%		Asia: 0.1%
		Other: 5%		

Table 2: Professional experience of respondents

Experience (yrs) (n=531)	Clients with aphasia seen per week (n=531)	Work setting (n=531)
<3: 17%	0: 13%	Outpatient Rehabilitation: 35%
3-5: 20%	1-5: 53%	Inpatient Rehabilitation: 34%
6-10: 18%	6-10: 20%	Acute/Sub-acute Hospital: 29%
11-15: 16%	11-15: 8%	Community: 25%
16-20: 13%	16-20: 3%	Private Practice: 24%
21-30: 13%	>20: 3%	University: 14%
>30: 3%		Long Term Care: 13%
		Early supported discharge: 10%
		Other: 8%

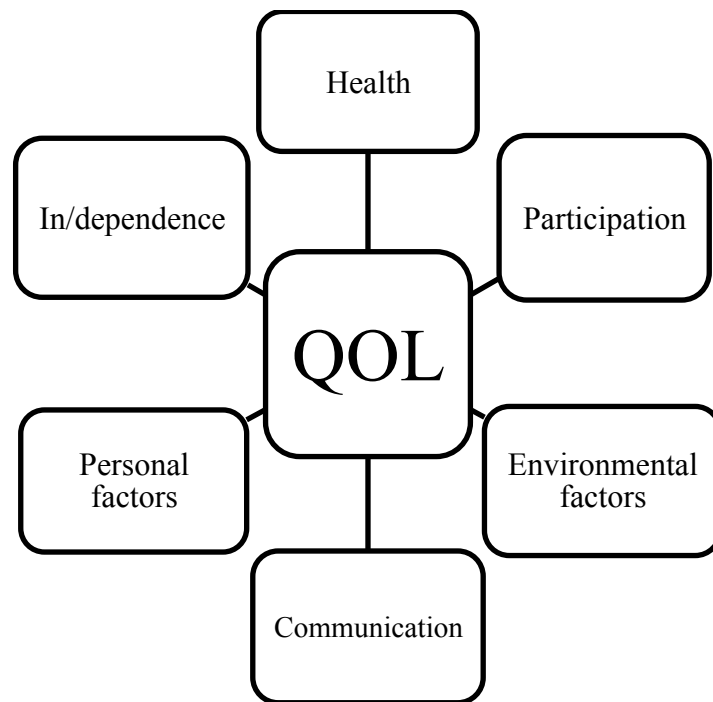


Figure 1: Factors influencing quality of life (QOL)

Table 3: Important perspectives on quality of life

Perspectives on quality of life	n %
Overall quality of life [e.g. an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (20)].	86%
Health-related quality of life [e.g. the impact of aphasia on people's ability to lead a fulfilling life. Typically incorporates subjective evaluation of physical, mental/emotional, family and social functioning (21)].	80%
Subjective and psychological well being [e.g. psychological functioning, subjective well-being and life satisfaction (22)]	78%
Positive or negative affect [e.g. Affect Balance Scale (23)]	26%
Other (please specify)	5%

Table 4: Important research areas for quality of life in aphasia (n=385)

Research areas	Response Percent
Efficacious interventions to improve quality of life in aphasia	58%
What factors influence quality of life in aphasia?	47%
How is the quality of life of people with aphasia affected by aphasia?	43%
Valid and reliable measures of quality of life for people with aphasia	42%
How is the quality of life of caregivers / family affected by aphasia?	31%
Comparative studies of different interventions to improve quality of life with aphasia	30%
Systematic reviews of interventions to improve quality of life in aphasia	23%
Cost-benefit analyses of different interventions for improving quality of life in aphasia	19%
Comparisons of quality of life in aphasia to other disorders	8%

Quality of life in aphasia: survey of clinical practice

About this survey

This survey aims to investigate perspectives and practices about quality of life in aphasia.

The information gathered through this survey will be used to identify a research agenda in this field.

This survey is being conducted by the Aphasia Committee of the International Association of Logopaedics and Phoniatrics (IALP). The members of the IALP Aphasia Committee are:

- Anu Klippi, Finland (Chair)
- Pelagie Beeson, USA
- Fofi Constantinidou, Cyprus
- Katerina Hilari, UK
- Simon Horton, UK
- Philippe Paquier
- Claire Penn, South Africa
- Anastasia Raymer, USA
- Linda Worrall, Australia
- Nada Zemva, Slovenia

The results of this survey will be presented at the IALP conference in Italy, 2013 as well as in the journal of the IALP, *Pholia Phoniatrica et Logopaedica*.

Thank you for your contribution.

Quality of life in aphasia: survey of clinical practice

About you

*1. What is your age?

- ☐ 18-20 years
- ☐ 21-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50-59 years
- ☐ 60 years or older

*2. What is your gender?

- ☐ Female
- ☐ Male

*3. What is your ethnic background?

*4. What languages do you speak?

Quality of life in aphasia: survey of clinical practice

***5. What country do you work in?**

***6. How many years of experience do you have working with people with aphasia?**

***7. In your current job, how many people with aphasia do you see each week?**

- ☐ 0
- ☐ 1-5
- ☐ 6-10
- ☐ 11-15
- ☐ 16-20
- ☐ more than 20

***8. Where do you work with people with aphasia? (Select all that apply)**

- ☐ Acute, sub-acute hospital
- ☐ Inpatient rehabilitation
- ☐ Outpatient rehabilitation
- ☐ Early supported discharge
- ☐ Community
- ☐ Long term care
- ☐ Private practice
- ☐ University
- ☐ Other (please specify)

***9. How do you define quality of life?**



Quality of life in aphasia: survey of clinical practice

***10. Which of the following perspectives on quality of life do you consider important? (Select all that apply)**

- ☐ Overall quality of life [e.g. an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 1993)].
- ☐ Health-related quality of life [e.g. the impact of aphasia on people's ability to lead a fulfilling life. Typically incorporates subjective evaluation of physical, mental/emotional, family and social functioning (Berzon et al., 1993)].
- ☐ Subjective and psychological well being [e.g. psychological functioning, subjective well-being and life satisfaction (Fuhrer, 1994).]
- ☐ Positive or negative affect [e.g. Affect Balance Scale (Bradburn, 1969)]
- ☐ Other (please specify)

Quality of life in aphasia: survey of clinical practice

***11. Which quality of life domains do you consider important to incorporate into your practice with aphasia? (Select all that apply)**

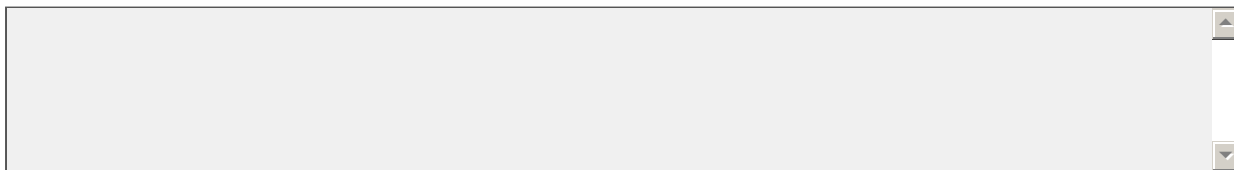
- ☐ affect
- ☐ body image
- ☐ communication
- ☐ daily activities
- ☐ energy
- ☐ financial security
- ☐ general/overall health
- ☐ in/dependence
- ☐ interpersonal relationships
- ☐ life satisfaction
- ☐ mobility
- ☐ pain
- ☐ personal outlook
- ☐ physical health
- ☐ psychological health
- ☐ psychosocial issues
- ☐ social activities
- ☐ social support
- ☐ spirituality
- ☐ the environment
- ☐ vitality
- ☐ Other (please specify)

Quality of life in aphasia: survey of clinical practice

***12. How do you use quality of life measures with people with aphasia? (Select all that apply)**

- ☐ As an assessment
- ☐ As an outcome measure
- ☐ I do not use quality of life measures with people with aphasia
- ☐ Other (please specify)

13. Which quality of life outcome measures or assessments do you use?



Quality of life in aphasia: survey of clinical practice

***14. Do you consider quality of life to be the primary aim of aphasia rehabilitation?**

☐ Yes

☐ No

15. What do you consider to be the primary aim of aphasia rehabilitation?



Quality of life in aphasia: survey of clinical practice

***16. Do you explore quality of life issues with people with aphasia in an interview format?**

☐ Yes

☐ No

***17. Do you assess quality of life in aphasia as part of initial assessment?**

☐ Yes

☐ No

***18. Do you explicitly include quality of life goals in therapy?**

☐ Yes

☐ No

Quality of life in aphasia: survey of clinical practice

*19. What are the greatest barriers (if any) to incorporating quality of life goals in your practice? (Select all that apply)

- ☐ Societal barriers (e.g. inadequate health care funding, cultural differences, attitudinal barriers)
- ☐ Organizational barriers (e.g. policy and procedural barriers, staffing barriers, resources)
- ☐ Personal barriers (e.g. professional value system does not acknowledge quality of life as a rehabilitation goal, lack of education or training in quality of life)
- ☐ None of the above
- ☐ Other (please specify)

*20. What are the greatest facilitators (if any) to incorporating quality of life goals in your practice? (Select all that apply)

- ☐ Societal (e.g. adequate health care funding, cultural, attitudinal)
- ☐ Organizational (e.g. policy and procedural, staffing, resources)
- ☐ Personal (e.g. professional value system, education or training in quality of life)
- ☐ None of the above
- ☐ Other (please specify)

21. Rank the three most important research areas for quality of life in aphasia by selecting 1 (most important), 2 and 3 in the boxes below.

How is quality of life of people with aphasia affected by aphasia

How is the quality of life of caregivers / family affected by aphasia

What factors influence quality of life in aphasia

Comparisons of quality of life in aphasia to other disorders

Valid and reliable measures of quality of life for people with aphasia

Efficacious interventions to improve quality of life in aphasia

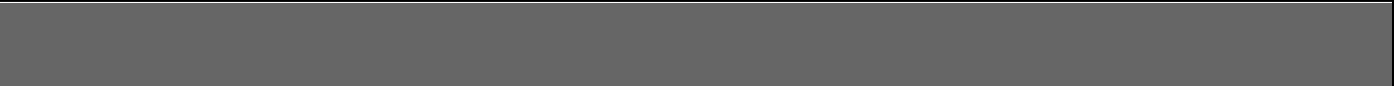
Systematic reviews of interventions to improve quality of life in aphasia

Comparative studies of different interventions to improve quality of life with aphasia

Cost-benefit analyses of different interventions for improving quality of life in aphasia

Other (please specify)

Quality of life in aphasia: survey of clinical practice



Thank you for your contribution.